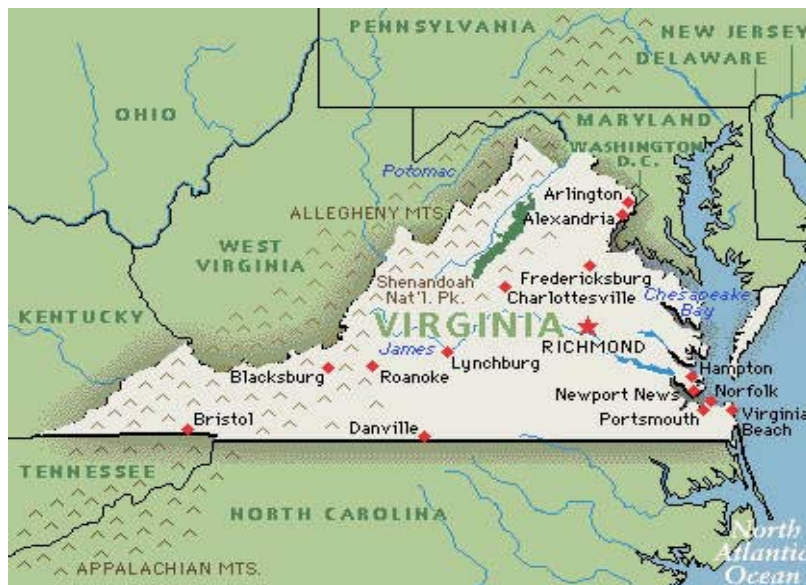


Personal Assistance Services Survey: Report of Findings



Prepared for:

Virginia Department of Medical Assistance Services

February 2004

Prepared by:

Kirsten Barrett, Ph.D.
Virginia Commonwealth University
Survey and Evaluation Research Laboratory

Table of Contents

	Page
Executive Summary	2
Study Purpose	6
Research Methodology	
Survey development and design	6
Survey distribution	6
Response rate	7
Description of the Survey Respondents	
Geographic distribution	7
Age, gender, and marital status	8
Living Arrangement and Dependent children	8
Educational attainment	8
Disability type	8
Personal Assistance Services at Home	10
Personal Assistance Services at Work	11
Summary	13
Limitations	13
Appendices	
Appendix 1 – PAS Survey Components	15

EXECUTIVE SUMMARY

The Virginia Department of Medical Assistance Services (DMAS) contracted with the Survey and Evaluation Research Laboratory (SERL) at Virginia Commonwealth University (VCU) to gain information from Medicaid recipients in DMAS's Home and Community Based Services Waiver Programs about the personal assistance services (PAS) received at home and, if applicable, at work.¹ Medicaid covers PAS in the home, at work, and at school for individuals in these waiver programs. The study was limited to waiver participants who received PAS at some point within the past year.

A total of 995 out of 1,670 surveys were completed and returned to yield a response rate of 60%. Survey respondents were evenly distributed across the Commonwealth of Virginia. The average age of respondents was 47 years with a range from 18 to 91. Sixty-one percent were female and 39% were male. The majority, 77%, were not married at the time of survey completion. Forty-eight percent reported having less than a high school education or equivalent. Twenty-seven percent of the respondents reported having one disability, 22% reported two disabilities, 19% reported three disabilities, and 32% reported between four and twelve disabilities. Cardiovascular impairment was cited by 36% of the respondents (n=306). Arthritis and diabetes were cited by 30% (n=258) and 27% (n=231) of the respondents respectively. The least frequently cited disabilities were substance abuse (n=6) and HIV/AIDS (n=3).

PAS at Home:

- The vast majority of respondents, 94% (n=933), reported receiving PAS at home. Local agency staff was cited as the primary provider of PAS services by 67% (n=560) of the respondents. Insurance was the primary source of payment for PAS at home.
- Fifty-one percent of respondents (n=459) rated their PAS services as excellent and 43% (n=390) rated their services as good to very good.

¹ Efforts were made to limit the sample to those less than 65 years of age. The analysis indicates that 97% of respondents were between the ages of 18 and 64.

- Sixty-two percent (n=540) of respondents reported receiving PAS six to seven days per week while 37% (n=326) reporting receiving PAS three to five days per week. Only 1% of respondents reported receiving PAS less than three days per week. The average number of hours per week of PAS was 63 with a median of 40. Hours per week ranged from a low of three to a high of 168 (24 hours a day, 7 days a week).
- Forty-six percent of respondents (n=430) reported receiving PAS for five to nine activities and 44% (n=409) reported receiving PAS for 10 to 16 activities. Most frequently cited were self-care activities like showering and bathing, preparing meals, and getting dressed. The least frequently cited activities were walking and going up and down stairs.

PAS at Work:

Only 2% of respondents (n=17) reported having a job for which they receive pay. Of those not currently working, only 1% (n=10) reported that they had worked at some point in the past six months. In addition, only 9% (n=72) of those not currently working reported that they would be able to work if PAS were made available to them in the workplace.

Analyses of data from employed respondents are limited due to a low “n” of 17. Although the following descriptive information is provided, it should be considered preliminary and should be interpreted cautiously.

- 7 of the 17 employed respondents reported working at a sheltered workshop, 3 reported secretarial or clerical work, and 2 reported technical or paraprofessional work.
- 13 out of 15 respondents reported working outside of the home; 8 of the 13 working outside of the home relied on public transportation.
- 12 of the 16 respondents had been at their current job for more than two years.
- 7 of the 14 respondents reported working between 24 and 35 hours per week; the remainder worked between 1.5 and 15 hours per week. Only 4 of 16 respondents reported a desire to work more hours per week.
- 10 of 14 respondents reported earning less than \$100 per month.
- 3 of 16 respondents reported having turned down a job, turned down increased hours, or turned down salary raises because they were afraid they might lose their Medicaid benefits.

Eight of 16 employed respondents received PAS in the workplace. The following information pertains to these individuals:

- Only 2 of the 8 report that their PAS at work is paid through their insurance and only 1 reported knowing that Medicaid will help pay for PAS in the workplace if the PAS helps the individual meet his/her personal care needs.
- 5 of the 8 respondents reported receiving between six to eight hours of PAS a day. Most reported receiving PAS five days a week (n = 6 out of 8).
- The most frequently cited activities for which individuals received PAS in the workplace were using the bathroom (n=7 of 8), eating (n=6 of 8), and transportation (n=5 of 8).
- 6 of the 8 respondents who currently receive PAS at work indicated that working would be impossible without the availability of PAS services.
- All 8 respondents reported that the quality of the PAS they receive at work is very good to excellent.

SUMMARY

PAS Survey respondents were quite limited in terms of their daily function. Forty-six percent of respondents (n=430) reported receiving PAS for five to nine activities and 44% (n=409) reported receiving PAS for 10 to 16 activities. In addition, the majority of respondents, 75%, required help completing the survey.

Most respondents reported receiving PAS at home six to seven days per week; the most frequent provider of services was local agency staff. The average number of PAS hours per week at home was 63 with a median of 40 hours.

Given the data about days and duration of PAS per week and the number of disabilities reported, it is not surprising that only 2% of respondents (n=17) were employed at the time of survey completion. Only 1% (n=10) were employed at some point in time in the past six months. Importantly, of respondents that were not employed, only 9% (n=72) indicated that they could work if PAS was available in the workplace.

SUMMARY (con't)

Respondents reported significant functional limitations and a need for intense PAS at home with multiple activities of daily living. Very few respondents reported being employed and most indicated that they would be unable to work even if PAS were provided in the workplace. These findings, along with other known barriers to employment such as transportation and job availability, suggest that employment is a significant challenge for those in DMAS's Home and Community Based Services Waiver Programs.

STUDY PURPOSE:

DMAS contracted with the Survey and Evaluation Research Laboratory (SERL) at Virginia Commonwealth University (VCU) to gain information from Medicaid recipients in DMAS's Home and Community Based Services Waiver Programs about the personal assistance services (PAS) received at home and, if applicable, at work. Medicaid covers PAS in the home, at work, and at school for individuals in these waiver programs. The study was limited to waiver participants who received PAS at some point within the past year.

RESEARCH METHODOLOGY:²

Survey Development and Design

DMAS worked with SERL to develop a number of closed-ended survey questions that fit into one of the following broad categories: PAS at home, PAS at work, and demographics. SERL staff formatted the survey and addressed question wording and question order issues. Then, key stakeholders at DMAS and the Department of Rehabilitative Services (DRS) reviewed and provided feedback on the survey prior to its distribution.

Survey Distribution

The *PAS Survey* was sent via first class mail to 1,730 individuals participating in DMAS's Home and Community Based Services Waiver Programs.³ The names and addresses for the mailing were provided to SERL by DMAS. SERL sent a pre-notification postcard to the entire sample ten days prior to the mailing of the survey. The postcard alerted individuals to the fact that they would be receiving a survey from SERL, on behalf of DMAS, within 10 to 14 days. Seven days thereafter, the mail survey was sent. A \$3 incentive was included in the first mailing along with a postage paid, return envelope. Two weeks after the first-wave mailing of the survey, a reminder postcard was mailed. Seven days thereafter, all non-responders were sent a second survey packet. This was identical to the first except for a revised cover letter and the exclusion of the \$3 incentive.

² The VCU Institutional Review Board (IRB) reviewed and approved the study protocol prior to the initiation of data collection.

³ Efforts were made to limit the sample to those less than 65 years of age. The analysis indicates that 97% of respondents were between the ages of 18 and 64.

A copy of the prenotification postcard, cover letter, survey, reminder postcard, and second-wave mailing cover letter can be found in Appendix 1.

Response Rate

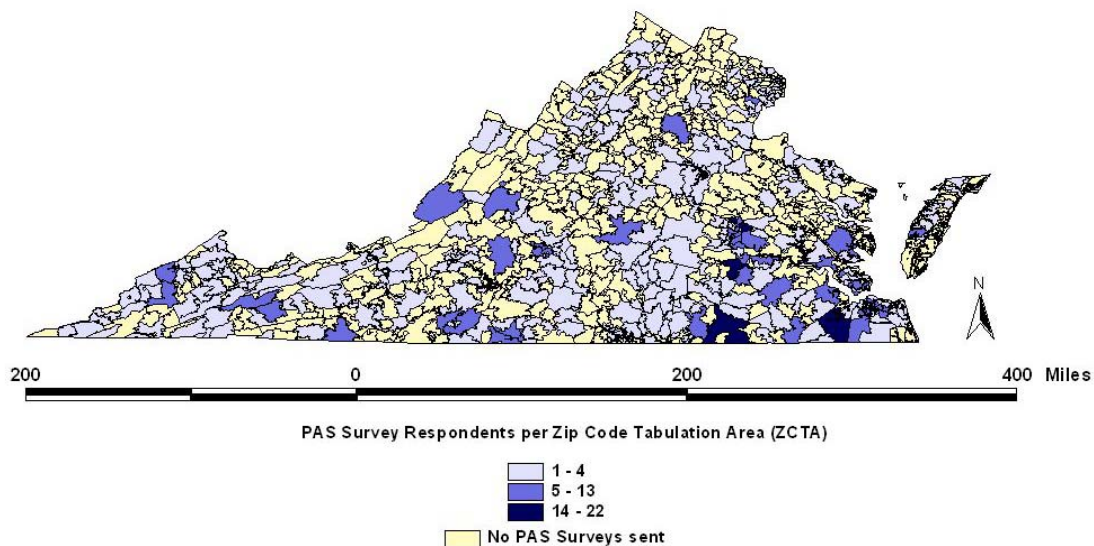
After accounting for bad addresses, deceased individuals, ineligible⁴, and refusals, the total sample size of 1,731 was reduced to 1,670. A total of 995 surveys were completed, 37 by telephone.⁵ Of all respondents, 75% (n=748) reported receiving help completing the survey. The survey response rate was 60%.

DESCRIPTION OF THE SURVEY RESPONDENTS

Geographic Distribution

Individuals across the Commonwealth responded to the survey. Figure one illustrates the distribution of survey respondents.

Figure 1 - Distribution of Respondents by Zip Code Tabulation Area



⁴ Ineligible respondents are those who were living in nursing homes, those living outside of Virginia, or those who were under the age of 18 at the time of survey completion.

⁵ A toll-free phone line and a TTY line were made available for survey respondents who were unable to complete the survey by mail.

Age, Gender, Marital Status

The average age of respondents was 47 years with a range from 18 to 91 years. Sixty-one percent of the respondents were female (n=599) and 39% were male (n=385). The majority of the respondents, 77%, reported not being married (n=743).

Living Arrangement and Dependent Children

Forty-seven percent of respondents (n=453) reported living in their own home or apartment; 43% (n=420) reported living in a relative's home or apartment. The majority of the respondents, 88% (n=846) reported having no dependent children living in their homes. Twelve percent of respondents (n=120) did have dependent children in their homes.

Educational Attainment

Forty-eight percent of respondents reported having less than a high school education (n=448), 32% reported a high school education or equivalent (n=294), and 20% reported having at least some college education (n=183).

Disability Type

Each respondent was asked to identify which disability category pertained to him/her from a list of eighteen provided. Respondents were instructed to check all of the disability categories that applied. Options included, but were not limited to, brain injury, spinal cord injury, cerebral palsy, mental health issues, and cardiovascular impairment.

Twenty-seven percent of the respondents checked one disability category only (n=236)⁶, 22% of respondents checked two disability categories (n=184), and 19% checked three disability categories (n=162). The remaining 32% checked between four and twelve disability categories (n=275).⁷

⁶ Of the 236 respondents checking only one disability category, 28% indicated that they had a spinal cord injury, 14% reported that they had multiple sclerosis, and 13% reported cerebral palsy.

⁷ 138 of the respondents failed to check any of the 12 disability categories on the survey. These respondents are excluded from the analyses related to disability type.

Cardiovascular impairment was cited by 36% of the respondents (n=306). Arthritis and diabetes were cited by 30% (n=258) and 27% (n=231) of the respondents respectively. The least frequently cited disabilities were substance abuse (n=6) and HIV/AIDS (n=3). Table one indicates the total number of respondents reporting each type of disability.

Table 1 - Disability Type of Respondents

Disability Type	# of Respondents	Percent of Total (N=857)
Cardiovascular impairment	306	36%
Arthritis	258	30%
Diabetes	231	27%
Epilepsy or seizures	192	22%
Brain injury	176	21%
Respiratory impairment	181	21%
Speech impairment	176	21%
Blind or visually impaired	151	18%
Learning disabilities	149	17%
Mental retardation	144	17%
Mental health issue	138	16%
Spinal cord injury	136	16%
Cerebral palsy	114	13%
Multiple sclerosis	84	10%
Deaf or hard-of-hearing	58	7%
Substance abuse	6	<1%
HIV/AIDS	3	<1%

NOTE: Respondents were instructed to check all disability categories that applied. Counts within disability type are unduplicated. Counts across category types are, to a degree, duplicated.

PAS AT HOME

The vast majority of respondents, 94% (n=933), reported receiving PAS at home. Local agency staff was cited as the primary provider of PAS by 67% (n=560) of the respondents. Twenty-seven percent of the respondents reported that a family member was the primary provider of PAS.

Sixty-two percent (n=540) of respondents reported receiving PAS six to seven days per week while 37% (n=326) reporting receiving PAS three to five days per week. Only 1% of respondents reported receiving PAS less than three days per week. The average number of hours per week of PAS was 63 with a median of 40. Hours per week ranged from a low of three to a high of 168 (24 hours a day, 7 days a week).⁸

Respondents were asked if the primary provider of PAS was paid for through insurance and/or some other source other than insurance. Of the 695 respondents who answered this question, 92% reported one method of payment for the primary provider of PAS; 8% reported a combination of insurance coverage and non-insurance coverage. Of those reporting one method of payment for PAS, 95% reported that insurance was the payment source.

Respondents were asked about the types of activities that they receive PAS for at home. A total of 16 activities were identified including, but not limited to, getting in and out of bed, walking, showering or bathing, eating, shopping, and transportation. Forty-six percent of respondents (n=430) reported receiving PAS for five to nine activities and 44% (n=409) reported receiving PAS for 10 to 16 activities. Most frequently cited were self-care activities like showering and bathing, preparing meals, and getting dressed. The least frequently cited activities were walking and going up and down stairs. Table 2 provides a listing of activities for which respondents received help.

⁸ The days per week of PAS is based on data from 875 respondents. The hours per week of PAS is based on data from 863 respondents. The total is less than the total number of respondents receiving PAS at home due to item non-response.

Table 2 - Activities for which Respondents Reported Receiving PAS

ACTIVITY	Number Receiving PAS for Activity	Percent Receiving PAS for Activity
Showering or bathing	845	91%
Preparing meals	814	87%
Getting dressed	796	85%
Housekeeping	772	83%
Doing laundry	757	81%
Shopping	594	64%
Getting in and out of bed	567	61%
Using the bathroom	494	53%
Transportation	466	50%
Getting around in wheelchair	459	49%
Home maintenance	350	38%
Managing money and bills	339	36%
Eating	335	36%
Walking	314	34%
Going up and down steps	266	29%
Using the phone	229	25%

NOTE: Respondents were instructed to check all activities which PAS provide help with. Counts within activity type are unduplicated. Counts across activity types are, to a degree, duplicated.

Respondents were asked about the quality of PAS provided in the home. Fifty-one percent (n=459) rated their PAS as excellent, 43% (n=390) rated their services as good to very good, and the remainder, 6% (n=59), reported their PAS as fair to poor. However, it should be noted that the majority of respondents reported receiving help filling out the survey. Therefore, perceptions about the quality of PAS may be those of family members or agency staff rather than the care recipient him/herself.

PAS AT WORK

Work Status and Ability to Work

Only 2% of respondents (n=17) reported having a job for which they receive pay. Of those not currently working, only 1% (n=10) reported that they had worked at some point in the past six months. In addition, only 9% (n=72) of those not currently working reported that they would be able to work if PAS were made available to them in the workplace.

Findings from Employed Individuals

Analyses of data from employed respondents are limited due to a low “n” of 17. Although the following descriptive information is provided, it should be considered preliminary and should be interpreted cautiously.

- 7 of the 17 employed respondents reported working at a sheltered workshop, 3 reported secretarial or clerical work, and 2 reported technical or paraprofessional work. The remaining 5 reported other types of jobs including making gift baskets and clergy work.
- 13 out of 15 respondents reported working outside of the home; 8 of the 13 working outside of the home relied on public transportation.
- 12 of the 16 respondents had been at their current job for more than two years.
- 7 of the 14 respondents reported working between 24 and 35 hours per week; the remainder worked between 1.5 and 15 hours per week. Only 4 of 16 respondents reported a desire to work more hours per week.
- 10 of 14 respondents reported earning less than \$100 per month.
- 3 of 16 respondents reported having turned down a job, turned down increased hours, or turned down salary raises because they were afraid they might lose their Medicaid benefits.

Eight of 16 employed respondents received PAS in the workplace. The following information pertains to these individuals:

- Only 2 of the 8 report that their PAS at work is paid through their insurance and only 1 reported knowing that Medicaid will help pay for PAS in the workplace if the PAS helps the individual meet his/her personal care needs.
- 5 of the 8 respondents reported receiving between six to eight hours of PAS a day. Most, reported receiving PAS five days a week (n = 6 out of 8).
- The most frequently cited activities for which individuals received PAS in the workplace were using the bathroom (n=7 of 8), eating (n=6 of 8), and transportation (n=5 of 8).
- 6 of the 8 respondents who currently receive PAS at work indicated that working would be impossible without the availability of PAS services.
- All 8 respondents reported that the quality of the PAS they receive at work is very good to excellent.

SUMMARY

PAS Survey respondents were quite limited in terms of their daily function. Forty-six percent of respondents (n=430) reported receiving PAS for five to nine activities and 44% (n=409) reported receiving PAS for 10 to 16 activities. In addition, the majority of respondents, 75%, required help completing the survey.

Most respondents reported receiving PAS at home six to seven days per week; the most frequent provider of services was local agency staff. The average number of PAS hours per week at home was 63 with a median of 40 hours.

Given the data about days and duration of PAS per week and the number of disabilities reported, it is not surprising that only 2% of respondents (n=17) were employed at the time of survey completion. Only 1% (n=10) were employed at some point in time in the past six months. Importantly, of respondents that were not employed, only 9% (n=72) indicated that they could work if PAS was available in the workplace.

Respondents reported significant functional limitations and a need for intense PAS at home with multiple activities of daily living. Very few respondents reported being employed and most indicated that they would be unable to work even if PAS were provided in the workplace. These findings, along with other known barriers to employment such as transportation and job availability, suggest that employment is a significant challenge for those in DMAS's Home and Community Based Services Waiver Programs.

LIMITATIONS

The *PAS Survey* was administered through the mail. Incentives and a second-wave mailing to non-responders were used to minimize non-response bias that is inherent in mail survey methodology. It is not known if those who responded are characteristically different than those who did not. However, a 60% response rate is encouraging along with the fact that there was representation across all regions of the Commonwealth.

A self-developed survey was utilized because an instrument was not available that adequately captured information relative to the study purpose. Further refinement of the *Personal Assistance Services Survey* is recommended based on the results of this study.

Recommendations include refining skip patterns and question order. In addition, survey content should be re-examined in light of the study findings. For example, additional questions about barriers to employment might provide valuable information about the ability of waiver participants to work.

APPENDIX 1

CONTENT FOR PRE-NOTIFICATION POSTCARD

The Virginia Department of Medical Assistance Services (DMAS) is trying to create a program that will provide ongoing Medicaid coverage for people with disabilities that work.

DMAS is working with the Survey and Evaluation Research Laboratory (SERL) to get information from you. Soon, you will get a survey in the mail from SERL. It will have questions about personal assistance services, work, disability status, and Medicaid. Please take the time to fill out the survey. The information you give will be very important as DMAS creates a Medicaid program that meets the needs of working people with disabilities in Virginia.

Sign with [to be determined]

[insert title]

Department of Medical Assistance

October 29, 2003

Dear [insert],

The Virginia Department of Medical Assistance Services (DMAS) is trying to create a Medicaid program that meets the needs of working people with disabilities. DMAS wants to hear from you. This mailing is being sent to people with disabilities. People that have problems with reading, writing, or understanding may get this survey. If this is the case, we hope that a family member, friend, or caregiver can help the person read this letter and fill out the survey.

The survey can be filled out in about fifteen minutes. It has questions about personal assistance services (PAS), work, disability status, and Medicaid. When filling out the survey, you can leave questions blank that you do not want to answer. The \$3 that we are giving you is a thank you for filling out and sending back the survey.

The survey has a number on the front page. This number lets us mail the survey again to people who do not send it back the first time. Information that you give us ***will not*** let you be known to DMAS or anyone else. In other words, information will be kept strictly confidential. **Also, if you now get Medicaid benefits, nothing in this letter or survey will change those benefits.**

If it is hard for you to fill the survey out, you can call the SERL at 1-800-304-9402 and answer the questions over the phone. If you need to use TTY, call Virginia Relay at 711 and ask to talk to SERL at 1-800-304-9402. SERL can take your call between 10:30am and 8:00pm Monday through Friday, between 11:00am and 4:00pm on Saturday, and between 4:00pm and 9:00pm on Sunday.

If you have any questions about this survey, please call Kirsten Barrett, Ph.D., SERL Project Director, at 804-828-8813 or send her an e-mail at kbarrett@saturn.vcu.edu.

It is very important that you return the survey. The information you give us will help DMAS create a Medicaid program for working individuals with disabilities in Virginia. Thank you for your time and effort!!

Sincerely,

A handwritten signature in black ink, appearing to read "Kirsten Barrett", written in a cursive style.

Kirsten A. Barrett, Ph.D., Project Director
Survey and Evaluation Research Laboratory

Personal Assistance Services Survey



Department of Medical Assistance Services

Fall

2003

Virginia Commonwealth University

Survey and Evaluation Research Laboratory

WHAT ARE PERSONAL ASSISTANCE SERVICES (PAS)?

- Some people with disabilities require regular support from others in order to manage daily personal activities. These services may be provided in the home, in the community, or at work. They are called "Personal Assistance Services" (PAS) or "Personal Care Services." Services include, but are not limited to, assistance with light housekeeping, dressing, bathing, walking, and shopping.
- PAS can be provided by family, friends, or paid staff from an agency.

SECTION I: PERSONAL ASSISTANCE SERVICES (PAS) AT HOME

1. Do you receive PAS at home?

☐¹ Yes ↘

☐² No →

Please skip to
question 5.

a. Who provides you with the **most** PAS in the home? Check one only:

- ☐¹ Family member (spouse / significant other, child, sibling, parent, etc.)
☐² Friend
☐³ Local agency staff
☐⁴ Other: _____

b. Is this person paid through your insurance (i.e., Medicaid)? ☐¹ Yes ☐² No

c. Is this person paid by some source other than your insurance? ☐¹ Yes ☐² No

2. When answering the next two questions, please consider all individuals, paid and unpaid, who provide you with PAS at home.

- a. On average, how many hours a day of PAS do you receive at home? _____(hours)
b. On average, how many days a week do you receive PAS at home? _____(days)

3. For which of the following activities do you receive PAS at home? Please check all that apply:

- | | | |
|--|--|---|
| <input type="checkbox"/> ¹ Getting in and/or out of bed | <input type="checkbox"/> ⁷ Getting dressed | <input type="checkbox"/> ¹³ Shopping |
| <input type="checkbox"/> ² Getting around in wheelchair | <input type="checkbox"/> ⁸ Preparing meals | <input type="checkbox"/> ¹⁴ Transportation |
| <input type="checkbox"/> ³ Walking | <input type="checkbox"/> ⁹ Eating | <input type="checkbox"/> ¹⁵ Home maintenance |
| <input type="checkbox"/> ⁴ Going up and/or down steps | <input type="checkbox"/> ¹⁰ Housekeeping | <input type="checkbox"/> ¹⁶ Managing money / bills |
| <input type="checkbox"/> ⁵ Using the bathroom | <input type="checkbox"/> ¹¹ Using the phone | <input type="checkbox"/> ¹⁷ Other: _____ |
| <input type="checkbox"/> ⁶ Showering or bathing | <input type="checkbox"/> ¹² Doing laundry | _____ |

4. Think about the person that provides you with the most PAS at home. Overall, how would you rate the services he/she provides you with at home? Check one only.

☐¹ Excellent ☐² Very good ☐³ Good ☐⁴ Fair ☐⁵ Poor

Comments about quality of PAS: _____

SECTION II: PERSONAL ASSISTANCE SERVICES (PAS) AT WORK

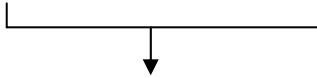
5. Are you currently doing any work for either pay or profit?

☐¹ Yes

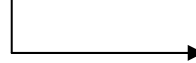


Are you self-employed?

☐¹ Yes ☐² No



☐² No



Have you worked in the past 6 months?

☐¹ Yes ☐² No

Would PAS make it possible for you to work?

☐¹ Yes ☐² No

Please skip to question 19.

6. What type of job do you currently have? Check one only:

- ☐¹ Executive, administrative, managerial (example: executive, business owner, manager, etc.)
- ☐² Professional (example: teacher, nurse, doctor, engineer, computer programmer, etc.)
- ☐³ Secretarial, clerical (example: typist, bookkeeper, clerk, secretary, etc.)
- ☐⁴ Technical, paraprofessional (example: drafter, teachers aide, nurse aide)
- ☐⁵ Skilled craft (example: mechanic, carpenter, electrician)
- ☐⁶ Service, maintenance (example: child care worker, janitor, truck driver)
- ☐⁷ Sales and related work (example: telemarketer, real estate sales, cashier)
- ☐⁸ Farming, fishing, forestry or related work (example: agricultural worker, logger, fisherman)
- ☐⁹ Manufacturing (example: assembly line worker)
- ☐¹⁰ Other: _____

7. How long have you been working at your current job? Please check one only:

☐¹ Less than 6 months ☐² 6 to 11 months ☐³ 1 to 2 years ☐⁴ More than 2 years

8. In general, how many hours do you work **each week**? _____ (# of hours)

9. Do you want to work more hours **per week** than you do right now? ☐¹ Yes ☐² No

10. On average, how much do you earn in one **MONTH**? Check one only:

☐¹ Less than \$100 ☐³ \$200 to \$499 ☐⁵ \$800 to \$1,099 ☐⁷ \$1,400 to \$1,699
☐² \$100 to \$199 ☐⁴ \$500 to \$799 ☐⁶ \$1,100 to \$1,399 ☐⁸ \$1,700 to greater

11. Have you ever turned down a job, turned down increased hours, or turned down salary raises because you were afraid you might lose your Medicaid?

☐¹ Yes ☐² No

NEXT PAGE —→

12. Do you receive PAS in the workplace?

☐¹ Yes

☐² No

Are you aware that Medicaid will help pay for PAS in the workplace if the PAS helps you meet your personal care needs?

☐¹ Yes

☐² No

If you had PAS in the workplace to help you meet your personal care needs, would you work more hours each week?

☐¹ Yes

☐² No

Please skip to question 18.

a. Who provides you with the most PAS in the workplace? Check one only:

☐¹ Family member (spouse / significant other, child, sibling, parent, etc.)

☐² Friend(s)

☐³ Co-worker(s)

☐⁴ Local agency staff

☐⁵ Other: _____

b. Is this the same person who provides your PAS at home?

☐¹ Yes

☐² No

c. Is this person paid through your insurance (i.e., Medicaid)?

☐¹ Yes

☐² No

d. Is this person paid by some source other than your insurance?

☐¹ Yes

☐² No

13. When answering the next two questions, please consider all individuals, paid and unpaid, who provide you with PAS services in the workplace.

a. On average, how many hours a day of PAS do you receive in the workplace? ____ (hours)

b. On average, how many days a week do you receive PAS in the workplace? ____ (days)

14. For which of the following personal care activities do you receive PAS in the workplace? Please check all that apply:

☐¹ Getting around in wheelchair

☐² Walking

☐³ Going up and/or down steps

☐⁴ Using the bathroom

☐⁵ Preparing meals

☐⁶ Eating

☐⁷ Managing money / bills

☐⁸ Using the phone

☐⁹ Transportation

☐¹⁰ Other: _____

NEXT PAGE →

SECTION II: PERSONAL ASSISTANCE SERVICES (PAS) AT WORK (con't)

15. What would best describe your work status if you did **NOT** receive PAS? Check one only:

- ☐¹ It would be impossible for me to work
☐² I could work but it would be very difficult
☐³ I could work but it would be a little difficult
☐⁴ I could work pretty easily

16. Think about the person that provides you with the most PAS in the workplace. Overall, how would you rate the services he/she provides you with at work? Check one only.

- ☐¹ Excellent ☐² Very good ☐³ Good ☐⁴ Fair ☐⁵ Poor

Comments about quality of PAS: _____

17. Are there times when you have needed PAS in order to be able to work, but there was no assistance available?

☐¹ Yes
↓

☐² No → **Please skip to question 18.**

a. Has your employment been negatively affected by the lack of PAS?

☐¹ Yes
↓

☐² No → **Please skip to question 18.**

b. How? Check all that apply:

- ☐¹ Missed day(s) of work
☐² Late for work
☐³ Unable to take on additional work hours
☐⁴ Unable to take on additional work responsibility
☐⁵ Other: _____

18. Where do you usually do your work?

☐¹ At a location outside of the home
↓

☐² Home → **Please skip to question 19.**

How do you usually get to work? Check one only:

- ☐¹ I drive myself
☐² A friend, family member, or co-worker drives me
☐³ Public transportation (i.e., bus, train, subway, taxicab, Para-transit)
☐⁴ Walk or ride wheelchair
☐⁵ Other: _____

NEXT PAGE →

SECTION III: GENERAL INFORMATION

19. Did a family member, friend, or caregiver help you complete this survey? ☐¹ Yes ☐² No

20. What is your age? _____

21. What is your gender? ☐¹ Male ☐² Female

22. Are you married? ☐¹ Yes ☐² No

23. Do you have dependent children living with you? ☐¹ Yes ☐² No

24. Where do you currently live? Please check one only:

☐¹ My own home or apartment

☐³ Friend's home or apartment

☐² Relative's home or apartment

☐⁴ Other: _____

25. What is your highest level of education? Please check one only:

☐¹ Less than high school

☐³ High school / GED

☐⁵ Bachelors degree

☐² Some high school

☐⁴ Some college / Associates degree

☐⁶ Graduate study or degree

26. **If you are working**, please check the **ONE** disability that interferes most with your ability to work.

☐¹ Mental illness

☐¹⁰ Mental retardation, autism, other developmental disabilities

☐² Substance abuse

☐¹¹ HIV / AIDS

☐³ Brain injury

☐¹² Deaf or hard-of-hearing

☐⁴ Spinal cord injury

☐¹³ Blind or visually impaired

☐⁵ Arthritis

☐¹⁴ Cardiovascular impairment (stroke, high blood pressure, etc.)

☐⁶ Multiple sclerosis

☐¹⁵ Respiratory impairment (asthma, emphysema, etc.)

☐⁷ Diabetes

☐¹⁶ Epilepsy / seizures

☐⁸ Learning disabilities

☐¹⁷ Speech impairment

☐⁹ Cerebral palsy

☐¹⁸ Other: _____

Now, please check any other disabilities that apply to you, **regardless of your current work status**.

☐¹ Mental illness

☐¹⁰ Mental retardation, autism, other developmental disabilities

☐² Substance abuse

☐¹¹ HIV / AIDS

☐³ Brain injury

☐¹² Deaf or hard-of-hearing

☐⁴ Spinal cord injury

☐¹³ Blind or visually impaired

☐⁵ Arthritis

☐¹⁴ Cardiovascular impairment (stroke, high blood pressure, etc.)

☐⁶ Multiple sclerosis

☐¹⁵ Respiratory impairment (asthma, emphysema, etc.)

☐⁷ Diabetes

☐¹⁶ Epilepsy / seizures

☐⁸ Learning disabilities

☐¹⁷ Speech impairment

☐⁹ Cerebral palsy

☐¹⁸ Other: _____

Thank you for completing this survey.

Please return it in the enclosed, pre-stamped envelope as soon as possible.

REMINDER POSTCARD CONTENT:

Last week, the Survey and Evaluation Research Laboratory (SERL) mailed a survey to you. On the survey, there were questions about personal assistance services (PAS), work, disability status, and Medicaid. It is very important that we get information from you. If you have already filled out the survey and sent it back, we say thanks. If you have not filled out and sent back the survey, please do so as soon as you can.

If you did not get the survey, please call Candace Price Stafford, SERL Mailroom Manager at 804-827-4320 (Voice) or email her at ceprice@vcu.edu. She will send you a new one. For TTY service, please call Virginia Relay by dialing 711. Ask them to help you get in touch with SERL by calling 1-800-304-9402. Thanks!

November 12, 2003

Dear [insert],

A few weeks ago, the Survey and Evaluation Research Laboratory (SERL) sent a survey to you. The survey had questions about personal assistance services (PAS), work, disability status, and Medicaid. The information you give will help Virginia's Department of Medical Assistance Services create a Medicaid program for working individuals with disabilities.

This mailing is being sent to people with disabilities. People that get this survey may have problems with reading, writing, or understanding. If this is the case, we hope that a family member, friend, or caregiver can help the person read this letter and fill out the survey.

If you have sent back the survey, we thank you. If you have not sent back the survey, we hope that you can take time to do this today. We have given you a new survey and a postage-paid return envelope in case the others were lost.

The survey has a number on the front page. This number allows us to send the survey to people who do not send it back the first time. Information you give us **will not** let you be known to DMAS or anyone else. In other words, information will be kept strictly confidential. **Also, if you now get Medicaid benefits, nothing in this letter or survey will change those benefits.**

If it is hard for you to fill out the survey, you can call the SERL at 1-800-304-9402 (Voice) and answer the questions over the phone. If you need TTY, please call Virginia Relay by dialing 711 and ask for a connection to 1-800-304-9402. The SERL staff can take your call between 10:30am and 8:00pm Monday through Friday, between 11:00am and 4:00pm on Saturday, and between 4:00pm and 9:00pm on Sunday.

If you have any questions about this survey, please contact Kirsten Barrett, Ph.D., SERL Project Director, at 804-828-8813 or send her an e-mail at kbarrett@saturn.vcu.edu.

It is very important that you return your survey. The information you give will let DMAS build a Medicaid program that meets the needs of working individuals with disabilities in Virginia. Thank you for your time and effort!!

Sincerely,

A handwritten signature in black ink, appearing to read "Kirsten A. Barrett".

Kirsten A. Barrett, Ph.D., Project Director
Survey and Evaluation Research Laboratory